

Energy and Commerce Subcommittee on Health
Examining Legislation to Improve Health Care and Treatment
Wednesday, December 9, 2015
Congresswoman Jaime Herrera Beutler

Thank you, Chairman Pitts, Ranking Member Green, and members of the Energy & Commerce Health Subcommittee for opportunity to advocate for parents with H.R. 3441, *The Accurate Education for Prenatal Screenings Act*.

Today, if you are an expectant mom, you are likely to be offered a non-invasive prenatal screening by your doctor– a screening that, its developers claim, can tell you if your baby has Down syndrome or other genetic conditions with “no confusion. Just simple clear results.”

The problem is that these screenings are not diagnostic tests – they have false positives and false negatives. In fact, studies have found that positive results are false up to half the time!

These screening are not regulated by the FDA and there are no requirements about what information is provided to doctors and parents.

A study that included information available online in the U.S. found that parents are receiving inadequate information about cell-free DNA prenatal screenings. Only 15% of the screenings’ websites pointed out that the test cannot rule out all fetal abnormalities. Some sites even stated that the test guarantees a healthy baby. Just over half the websites stated that an invasive test is required to confirm a positive non-invasive screening result, and only a quarter mentioned the importance of pre-test counseling with a health care professional.

Families are empowered when provided clear, accurate and up-to-date information. When that information is limited, unreliable or inaccurate, families are placed at a dangerous disadvantage.

The bill requires the appropriate HHS agency to develop unbiased, evidence-based education materials for providers and expectant parents that help them better understand cell-free DNA prenatal screenings.

Thank you again for the opportunity to advocate for parents and doctors to have complete and correct information about the advantages – and limitations – of prenatal screenings. I respectfully urge the committee to act expeditiously on H.R. 3441, *The Accurate Education for Prenatal Screenings Act*.